



# **The Confidentiality of HIV/AIDS Test Results and the Privacy of Persons Living With HIV/AIDS from the Perspectives of Human Rights in Nigeria: An Appraisal**

<sup>1\*</sup>Aminu Wada & <sup>2</sup>Idris Musa

<sup>1</sup>Department of Law

Jigawa State College of Education and Legal Studies,  
PMB 1009 Ringim, Jigawa State, Nigeria  
Corresponding author email: aminuwadarng@gmail.com

<sup>2</sup>Department of Sharia

Jigawa State College of Education and Legal Studies,  
PMB 1009 Ringim, Jigawa State, Nigeria

## **ABSTRACT**

Obviously, people living with HIV/AIDS (PLHAs) deal with the medical impact of HIV/AIDS, their status may result in or be a consequence of social factors, including violation of human rights. The links between health and human rights of privacy and confidentiality are complex and multidirectional. In Nigeria and elsewhere, PLHAs frequently experience gross violations of human rights, such as breaches of privacy and confidentiality, termination of employment, ejection from housing, and other forms of discrimination and social exclusion. These violations affect not only PLHAs; family members and others perceived to be at high risk of HIV/AIDS (such as sex workers) may experience discrimination and subsequent increased risk, thus perpetuating the cycle. This paper appraise the manner upon which the confidentiality of the HIV/AIDS test results being handled and the privacy of persons living with HIV/AIDS (PLHAs) supposedly being protected in Nigeria with a view of finding a solutions to the violations of their rights. This paper found that; the rights of people living with HIV/AIDS are seriously affected by gross violations of their rights and it finally recommended the review of confidentiality law to be revisited and drafted to conform with internationally best practice laws and guidelines on HIV//AIDS.

**Keywords:** Privacy. HIV/AIDS, Human Rights and Confidentiality

## **INTRODUCTION**

In Nigeria, as in other parts of Africa, persons are living with HIV/AIDS (PLHAs) often if not always, experience discrimination and stigmatisation by family or in the workplace, at school, and in other settings including prisons, health care and religious institutions. These violations are often driven by fear due to the lack of knowledge, prejudice, and a dangerously misguided and misinformed desire to protect public health. In fact, public health often provides an added and compelling justification for safeguarding human lives, despite the respect, protection, and fulfilment that they merit in their own profession. In the context of HIV/AIDS, an environment in which human rights are respected ensures that vulnerability to HIV/AIDS is reduced through information and empowerment, that those infected with and affected by HIV/AIDS live a life of dignity without discrimination, and their personality is squarely protected while societal impact of HIV infection is alleviated Haaserman, J.(1992).

Human rights are inherent in man; they arise from the very nature of man as a social animal. Human rights constitute a body of unique virtues which are highly cherished and valued from inception of time. In a paper presented by Justice Izuako at a seminar titled “HIV/AIDS and Human Rights: The

Role of the Judiciary,” human rights were described in the words of former Indian Chief Judge, Justice B.N. Bhagwati, as not ephemeral, not alterable with time, space and circumstances. They are not the product of philosophical whim or political fashion. They have their origin in the fact of the human condition, and because of this origin, they are fundamental and inalienable. More specifically, constitutions, conventions, or governments do not confer them. These are the instruments, the testaments of their recognition; they are important, sometimes essential elements of the machinery for the protection and enforcement of human rights, but they do not give rise to human rights. Human rights were born not of humans but with humans. AIDS Law Project, South Africa (1997).

## **CONCEPTUAL FRAMEWORK**

### **1. Human Rights**

The concept of human rights is grounded in concepts of human dignity and equality, which can be found in most cultures, religions and traditions that are today reflected in many legal systems. People Living with HIV/AIDs have the same fundamental social, cultural, civil, and political rights as any other person by virtue of their humanity. These rights are universal, indivisible, interdependent, and interrelated. The need to protect and promote the rights of PLHAs is predicated on the standards contained in the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights (ratified by Nigeria in 1993), and domesticated by means of the African Charter on Human and People’s Rights (Ratification and Enforcement Act, Cap 10, LFN, 1990) and other international human rights instruments, such as International Labour Organisation (ILO) instruments concerning discrimination in employment and occupation, termination of employment, protection of workers’ privacy, and safety and health at work. Many of these fundamental rights are enshrined in Chapter IV of the Federal Constitution of Nigeria 1999.

### **2. Right to Privacy**

The right to privacy is provided for under Article 12 of the UDHR. It implies that no one shall be subjected to arbitrary interference with his privacy, family, home, or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference. The Nigerian Constitution of 1999 in S.37 guarantees the right to privacy of every citizen. This right is also guaranteed under Article 12 of the UDHR. Similarly, Article 6 of the ACHPR provides for the protection of this right. The entrenchment of this right in the Constitution is very important. This reason is that Nigeria being a common law country does not have effective legal regime for the protection of individual privacy in her legal system. Applying literal rule of interpretation of the above stated law, one may not be wrong to argue that patient’s right to privacy is not within the contemplation of this provision, because doctors are not expected to diagnose their patient at home, or via telephone and telegraphic communication, especially in a country like Nigeria which is still under developed (Salihu. 2018).

In other jurisdictions, such as South Africa, Britain, and Canada, the right to privacy has been held to encompass obligations to respect physical privacy, including the obligation to seek informed consent to HIV testing and privacy of information, including the need to respect confidentiality of all information relating to a person’s HIV status. (Canadian Legal Network on HIV/AIDS.Legal/Ethical Issues Raised by HIV/AIDS).

### **2. Person Living with HIV/AIDS (PLH)**

These are class of people who are tested and being found carrying the virus in their blood stream, they are termed as HIV/AIDS positive patent. In this context, respect for the privacy of PLHAs and confidentiality of test results are crucial to the prevention of the HIV epidemic. Failure to respect the privacy of a patient who is HIV positive may result in a number of consequences. Testing without informed consent damages the credibility of health services and may discourage those needing services from obtaining them. Mandatory testing can create a false sense of security, especially among people who are outside its scope and who use it as an excuse for not following more effective measures for protecting themselves and others from infection.

### **3. Confidentiality**

Confidentiality refers to the ethical, professional, and/or legal duty of the health care professional and other professionals, such as lawyers and social service providers, not to disclose to anyone else without authorisation, information that was given to or obtained by the professional in the context of his/her professional relationship with a client (Bartlett. 1988). It embraces intimate matters, which

include sexual relationships, health status, and illicit drug use. Due to the special relationship that exists between the health care provider and the patient, a divulgence of information by the health care provider without the express consent of the patient amounts to a breach of confidentiality, except in cases where the health care provider shares information about a patient with his/her colleagues in the course of treating the patient.

#### **4. Disclosure**

Disclosure is a neutral term in the context of HIV/AIDS. It refers to the act of informing any individual or organisation (e.g., health authority, employer, school) of the HIV status of an infected person, or it refers to the fact that such information has been transmitted, by any means, by the person him or herself or by a third party, with or without consent. UNAIDS and WHO encourage “beneficial disclosure.” This is disclosure that is voluntary, respects the autonomy and dignity of the affected individuals, maintains confidentiality as appropriate, leads to beneficial results for those individuals and for their families and sexual and drug-injecting partners, leads to greater openness in the community about HIV/AIDS, and meets the ethical imperatives of the situation where there is need to prevent onward transmission of HIV (UNAIDS and WHO). (Nigerian National Policy on HIV/AIDS and STIs, 1997) Such beneficial disclosure, with its elements of voluntarism and confidentiality, not only maintains ethical principles but also serves a direct public health function because it encourages people to access HIV prevention and care services. It does this by establishing a climate of trust between health care providers and those who need HIV services, allaying their fears and respecting them as people who can and will make the right decisions regarding their behaviour. Beneficial disclosure also serves the goal of opening up the HIV/AIDS epidemic. As more people feel able and willing to disclose their status, there grows a critical mass of individuals and families within a community, and indeed within a nation, who are openly involved in dealing with the epidemic in positive and supportive ways. As a consequence, discrimination, stigma, and secrecy are reduced.

### **HIV/AIDS TESTING: CONTEXTUAL ANALYSIS**

#### **1. Testing Without Consent**

In Nigeria, the right to privacy of PLHAs is often violated when an HIV test is conducted without informing the patient or seeking his or her consent. (Haaserman, 1992) This appears to be common practice in both private and public health care settings; pregnant women who attend antenatal clinics are often tested for HIV without being informed. There are reports of physicians and hospitals in Nigeria having performed HIV antibody tests without obtaining specific informed consent, relying instead on the implied consent to treatment and blood tests that hospital patients typically provide. This is often called “routine” HIV antibody testing—that is, testing without the specific informed consent of the patient, followed often by rejection and other negative consequences.

According to a statement from the consultation on Testing and Counselling for the HIV Infection published by the World Health Organisation (WHO) (1992), “mandatory testing and other testing without informed consent has no place in an AIDS prevention and control programme.” The statement explains that because of stigmatisation and discrimination directed at HIV-infected people, individuals who believe they might be infected tend to go “underground” to escape mandatory testing, (Haaserman, 1992).

By the Declaration of Commitment on HIV/AIDS, UNGASS 26th special session, UN Doc A/Res/S-26/2 (2001) New York, USA, the experience has shown that some doctors conduct HIV tests on patients without their consent because they feel that in order to be able to protect themselves, they need to know the patient’s HIV status, contrary to the principle that precautions need to be applied universally. It has also been discovered that doctors engage in these acts because they do not seem to understand why HIV testing should be treated differently from other medical tests. With few exceptions, testing for HIV without specific proper informed consent is unconstitutional, being contrary to Section 37 of the 1999 Constitution of Nigeria. (Salihu, 2018).

#### **2. Testing of Donors**

The mandatory HIV testing of donors of blood, organs, tissue, ova, semen, or other human body parts and fluids has been universally endorsed as an essential and effective means of preventing the spread of HIV. Although the current test will not detect all HIV-positive donors, the introduction of HIV testing has nonetheless greatly improved the safety of the blood supply.

### **3. Testing for Research Purposes**

A more controversial issue than the testing of donors is whether epidemiological screening should be allowed without informed consent. With the introduction of a test for HIV in 1985, it became possible to investigate how widespread the epidemic had become and to monitor how patterns of infection were evolving. Information of this kind is of great value in designing, implementing, and monitoring programmes for the prevention and control of HIV. Voluntary or compulsory testing cannot provide this information because it provides a flawed view of the prevalence of HIV in the population. (Jayaraman, 1998) In a voluntary testing regime, those who are at highest risk of HIV infection and people who are otherwise marginalised in society may be over- or under-represented in the group of individuals tested. Similarly, mandatory testing or screening will not provide information of sufficient accuracy or completeness for public health surveillance purposes, as persons at risk of HIV infection may selectively avoid contact with health services or testing activities, creating unpredictable participation bias. Therefore, as an alternative to voluntary or mandatory testing of individuals for epidemiological research, unlinked anonymous screening (UAS) programs have been undertaken in some parts of the world, for example, in Canada and the United States. UAS, also known as “blinded” testing, is performed by systematically testing samples of blood left over after having been collected and tested for medical reasons other than HIV testing (Foreman, 1998)..

### **PUBLICATION AND COMMUNICATING HIV/AIDS STATUS**

The right to privacy is also violated in the media when information about the HIV/AIDS status of a PLHA is circulated without first getting consent of the individual. An example is the case of a policewoman in Nigeria whose HIV status was revealed to the public by the media and resulted in her demotion. In Canada, it has been held in the case of *Jean Pierre Valiquette v The Gazette* that a personal action started based on violation of an individual’s human right would even survive the plaintiff. In the case, a journalist published an article about an HIV-positive male teacher on the front page of a newspaper without seeking the consent of the teacher. Although the teacher’s name was not mentioned in the article, he could be identified because of the indirect information contained in the article. This publication was held to encroach on the privacy of the teacher, and he was therefore awarded damages. Although this decision is not binding in our courts, it is of persuasive authority in the absence of a direct judicial authority in Nigeria (Salihu. 2018).

### **TESTING IN THE WORKPLACE**

In the workplace, breach of privacy may arise when an employee is made to undergo mandatory HIV testing by his employer. It may also arise where a health worker reveals the result of an employee’s HIV test to his employer without the consent (and often without the knowledge) of the employee. Failure to protect the privacy of a PLHA in the workplace may hinder other workers from finding out their HIV status, which will consequently fuel the spread of the epidemic. Experience of many PLHAs in Nigeria indicates gross breach of privacy in the workplace, (Nigerian National Policy on HIV/AIDS and STIs, 1997).

### **CONFIDENTIALITY AND HIV/AIDS TEST**

Confidentiality is an ethical principle particularly relevant in the provision of health care. The principle of confidentiality encompasses the view that a person should be entitled to privacy with regard to his or her most personal physical and psychological information. It is also part of the basis for an effective relationship between patient/client and health care provider, and hence the basis for the effectiveness of many public health interventions that rest on these relationships. Only if a person feels sure that the health care provider will keep confidential any information provided would he/she come forward and share information that may be critical to making decisions about effective clinical care and treatment.( UNAIDS and WHO 1992)

Thus, health care professionals have long recognised and respected their duty and the need to protect the confidentiality of their patients. Because of the need to protect confidentiality in order to provide effective health care, health care professionals also recognise that they should normally only disclose highly personal information, such as HIV status, with the informed consent of the patient. For example, Rule 18 of the professional conduct for medical and dental practitioners in Nigeria provides that any information about a patient that comes to the knowledge of a practitioner shall be treated with

utmost secrecy and that the medical records of a patient are strictly for the consumption of the patient alone. In the context of HIV/AIDS, confidentiality applies to a person's HIV/AIDS status and requires that health authorities seek the consent of the person infected for the disclosure of his/her HIV/AIDS status to others. Confidentiality also includes the expectation by a person with HIV/AIDS that his/her status will not be disclosed by other persons without his/her consent.

The ethical principles of confidentiality and informed consent, which have private and public health benefits, should be distinguished from "secrecy," which is a state of affairs often resulting from fear, shame, and/or a sense of vulnerability. Whether secrecy is maintained depends solely on the personal motives of those who hold the secret. As discussed above, motives to maintain secrecy in the context of HIV/AIDS involve not only fear and shame, but also denial, fear of rejection, stigma, and discrimination. To the degree that secrecy harms the infected and the uninfected and undermines an individual's, family's, or community's ability to cope positively with HIV/AIDS, it should be strongly combated. UNAIDS and WHO are of the view that the secrecy surrounding HIV/AIDS and the related stigma, denial, and discrimination, can best be countered by a greatly increased commitment to beneficial disclosure and ethical partner counselling as described below.

Partner counselling or partner notification involves the process of contacting sexual and/or injecting partners of an HIV-positive person (in this context often called the "source" or "index" client or patient) in order to advise these partners that they may have been exposed to HIV and to encourage them to obtain HIV counselling, testing, and, where applicable, treatment. This must be done with the consent of the patient. The objectives of this kind of disclosure are to:

1. prevent HIV transmission to people who may be exposed either sexually or through needless haring, and
2. Improve care and support for PLHAs.

Partner counselling can be undertaken by the source client or patient him/herself, by the health care provider, or through the combined efforts of both.

Source referral: HIV-positive people are encouraged to counsel partners concerning their possible exposure to HIV. This takes place without the direct involvement of health care providers. In this approach, the health care provider works with the HIV-positive person regarding the nature of the information to be passed on to their partner(s) and ways of doing it. (Johnson, 1992)

Provider referral: An HIV-positive person gives the name(s) of his/her partner(s) to a health care provider who then confidentially counsels the partner(s) directly. In this approach, the health care provider does not disclose the name of the HIV-positive person to the partner but only provides the information that the partner is likely to have been exposed to HIV infection. This is done with the consent of the source client or patient. The health care provider for example, obtains the names of his/her patient, and the result of HIV test is available to him but allows the third party to know the status this is one of the main reasons why protecting the confidentiality of HIV/AIDS-related information is so important is that the revelation of a person's HIV status (and, often, a person's sexual orientation or drug use) exposes people to stigmatisation, discrimination, and rejection. People with HIV or AIDS would have less reason to fear disclosure of their HIV status if that disclosure did not expose them to such negative reactions and if they were better protected against discrimination, (Johnson, 1992).

### **CLEAR VIOLATION OF RIGHTS**

So many reports have appeared in most of the official reports of PHLHA's to the incidences of either violations or discriminations The general rule that HIV testing in Nigeria should only be undertaken with the specific informed consent of the person being should be informed before the performance of the test that an HIV-related test will be conducted and given adequate information about the nature and purpose of the test. (Nigerian National Policy on HIV/AIDS and STIs, 1997).

Where people fear forced testing or disclosure involving lack of confidentiality, they will avoid HIV counselling, testing, treatment, and support because these are likely to mean that their HIV status will become known against their will and they will face stigma, discrimination, lack of privacy, and other negative effects. Thus, fear of lack of confidentiality and forced disclosure may drive people away from HIV services, thereby reducing opportunities to encourage and empower people to change their behaviour in order to either avoid getting infected or avoid passing on their infection. It may also

drive people away from other health care services, such as antenatal care, or from participating in blood donation.

### **STIGMA AND DISCRIMINATION**

Stigma is often associated with discrimination and human right and has been defined in various ways. (Goffman,1963) defined stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society. Stigma can stem from a particular characteristic, such as a physical deformity, or from negative attitudes towards a group, such as homosexuals or prostitutes. Under Goffman's definition, society labels an individual or group as different or deviant. (Jones et al 1984) defines stigma as an attribute that links a person to undesirable characteristics. (Crocker, 1998) indicated that stigmatized individuals are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context. Others have defined stigma as societal processes that are linked to societal power structures. (Link, 2001) Stigmatization can lead to prejudicial thoughts, behaviours, and actions on the part of governments, communities, employers, health care providers, co-workers, friends, and families. (Cameron, 1993).

#### **Findings:**

By this research, It was found that, the breach of privacy may arise when either a health worker or medical personnel who conduct a medical screening revealed the result which is positive to a third party, or a person who is traditionally saddled with responsibility of keeping the confidentiality of PLHA decided to revealed the confided result to a third party, in the event that the result of the test turn to be positive, in this two circumstances, the privacy was flagrantly abused, hence the right of persons as provided by relevant laws was breach, and tendency of stigmatisation will come in to play, hence defeating the objective of the HIV/AIDS laws.

### **RECOMMENDATIONS**

1. Confidentiality laws in Nigeria should be reformed /drafted to conform to the recommendations in the International Guidelines on HIV/AIDS and Human Rights, which read as follows: "General confidentiality and privacy laws should be enacted. An independent agency should be established to redress breaches of confidentiality. Provision should be made for professional bodies to discipline cases of breaches of confidentiality as professional misconduct under codes of conduct.(Zierler et al.2000).
2. There should be training of health providers on the respect for human rights of PLHA patients. An ombudsman should be established to facilitate lodging of complaints by patients who are aggrieved by the way he/she has been treated by a health worker.
3. National HIV/AIDS programs need to strengthen their health systems and block all barriers to treatment and prevention programs.
4. Antidiscrimination legislation should be made that will protect vulnerable groups, such as women, children, and PLHAs, from unfair discrimination.
5. Professional bodies, policymakers, legislators, interest groups, and the entire public should be sensitised to the human rights of PLHAs.
6. NGOs should be involved in sensitising the legislators to the need to make an antidiscrimination law on HIV/AIDS. Also, the NGO community should pursue test cases dealing with the human rights of PLHAs.
7. The courts have a great role to play in ensuring that PLHAs are not discriminated against. As a back up to the court system, an independent human rights body should be set up to hear cases on discrimination against PLHAs. This should ensure speedy trial of cases brought by PLHAs.
8. Government and NGOs should embark on HIV/AIDS education among religious leaders/groups.

### **CONCLUSION**

Finally, by this appraisal the privacy of persons living with HIV/AIDS from the perspective of human rights and the confidentiality of HIV/AIDS test results in Nigeria, has curiously reflect the basic problems associated with HIV test and the right of privacy is possibly violated to the extent that, the victims may not be assured of his confidentiality as to the status of his health can actually be revealed to the third party thus encouraging stigmatization.

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